

NHPCO Project ECHO 2023

Equity Where It Matters

Topic: Supporting Hispanic Patients at the End of Life -

Common Challenges and Cultural Considerations when providing End-of-Life Care to the Hispanic and Latino population

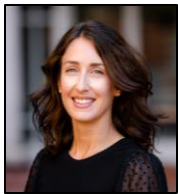
Date: Thursday, September 21, 2023

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Disclosures

Disclosure

The faculty and planners for this educational event have no relevant financial relationship(s) with ineligible companies to disclose.

Data Collection

In order to support the growth of the ECHO® movement, Project ECHO® collects participation data for each ECHO® program. Data allows Project ECHO® to measure, analyze, and report on the movement's reach. Data is used in reports, on maps and visualizations, for research, for communications and surveys, for data quality assurance activities, and for decision-making related to new initiatives.

Evaluation

You will be receiving an email with a link to complete a short survey about this session. Please complete the survey within 48 hours. We ask all participants to take the survey as it will help us to improve future sessions.

Ground Rules and Video Teleconferencing Etiquette

- This is an all share-all learn format; judging is not appropriate
- Respect one another – it is ok to disagree but please do so respectfully
- Participants – introduce yourself prior to speaking
- One person speaks at a time
- Disregard rank/status
- Remain on mute unless speaking and eliminate or reduce environmental distractions to improve sound/video quality
- Use video whenever possible; make eye contact with the camera when you are speaking
- **Do not disclose protected health information (PHI) or personally identifiable information (PII)**

Today's Agenda

- Introduction of Faculty – NHPCO Team
- Didactic Presentation – Faculty
- Case Study Presentation – Faculty
- Discussion – Session Participants, Faculty, and NHPCO Team
- Key Takeaways – Faculty and NHPCO Team
- Closing Remarks – NHPCO Team

Session Faculty



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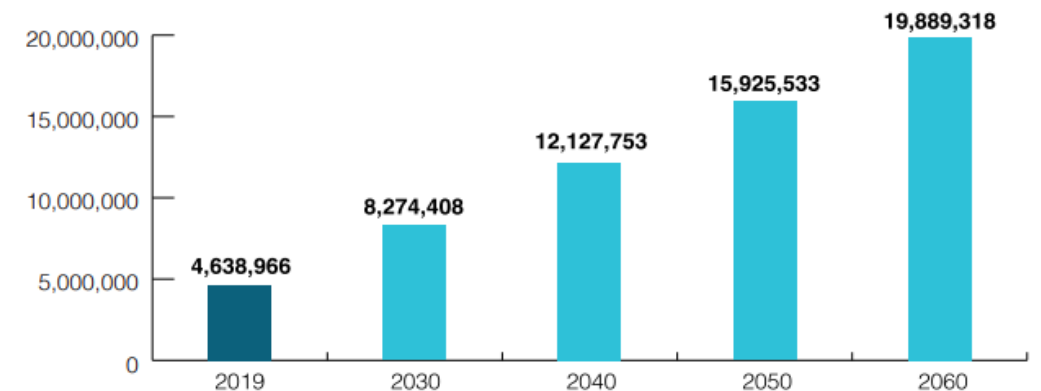
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Didactic Presentation

Background

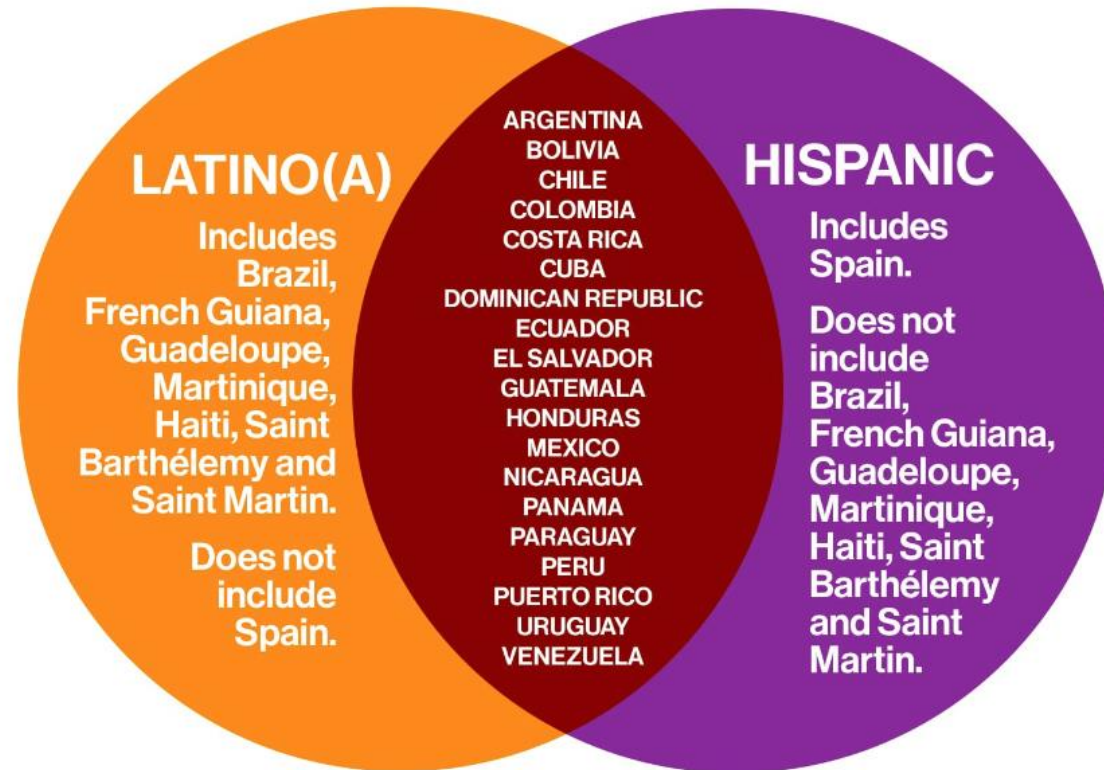
- Latinos are the largest minority in the United States
- As of 2020, 18.5% (60.6 million) of the United States (US) population identified as Hispanic/LatinX
- Between 2010 and 2020, more than half (51.1%) of the total increase in the US population came from this community's growth
- The Hispanic American population age 65 and older was 4,638,966 in 2019 and is projected to grow to 19.9 million by 2060 (will be 21 % of the older population)

Population and Projections of Hispanic Americans Age 65+: 2019 to 2060



Source: U.S. Census Bureau, Population Estimates and Projections, 2017 (revised).

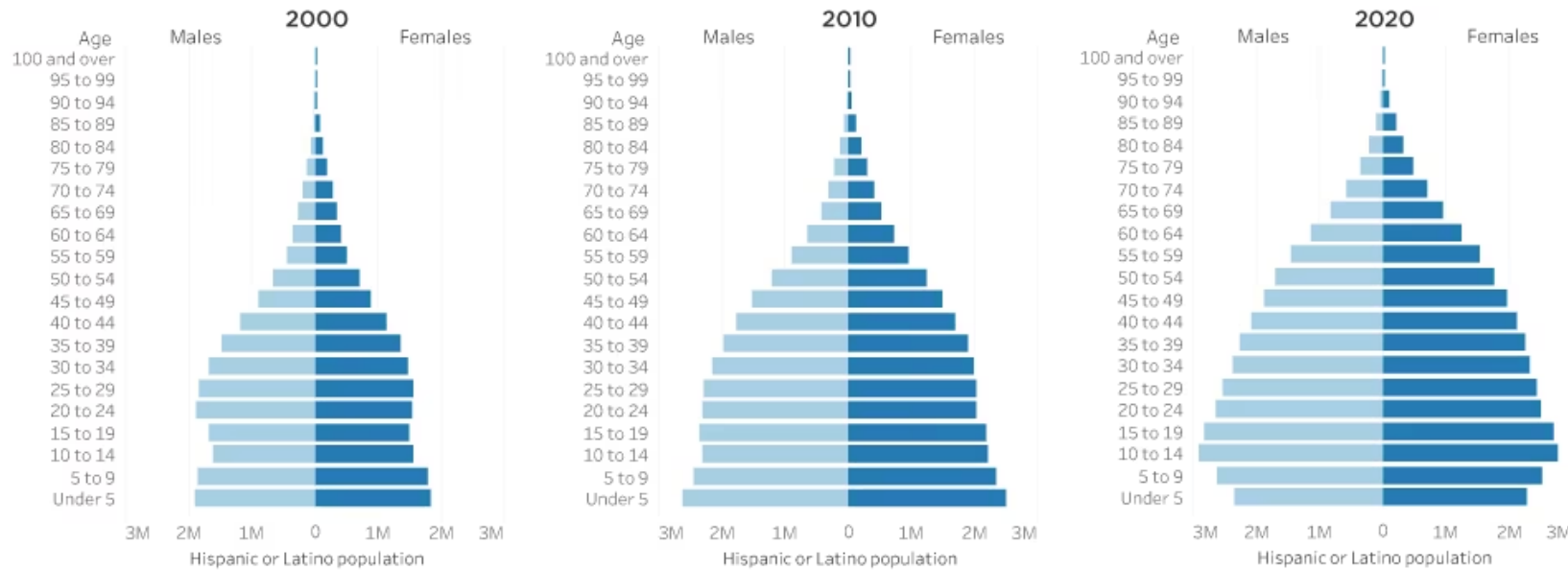
Hispanic, Latinos, Latin American...LatinX?



Source: Seaman Giannina. "Hispanic, Latino, Latin(x), Spanish: Clarifying Terms for Hispanic Heritage Month". Ketchum, 18 September 2020, <https://www.ketchum.com/hispanic-latino-latinx-spanish-clarifying-terms-for-hispanic-heritage-month/>

While younger than the non-Hispanic population, the Hispanic or Latino population has aged faster over the past decade, according to 2020 Census data.

Figure 1.
Population Pyramids for the Hispanic or Latino Population in the United States:
2000, 2010 and 2020
(In millions)



Source: U.S. Census Bureau, Census 2000 Summary File 1 (SF1), 2010 Census Summary File 1 (SF1) and 2020 Census Demographic and Housing Characteristics File (DHC).

What We Know...

- Despite the knowledge that the early use of hospice and palliative care significantly improves the quality of life, symptoms, better utilization of health care resources, and increases the likelihood of dying at preferred location and the Hospice Medicare Benefit been available for almost 4 decades, very little research has focused specifically on Hispanics
- Almost no research among undocumented Hispanic immigrants who may experience even further barriers due to their lack of eligibility for U.S. healthcare benefits
- Hispanic patients are more likely to agree to ineffective and burdensome high-intensity treatment at the EOL
- Low Advanced Care Planning engagement among Latinos

[1] Cardenas V, Fennell G, Enguidanos S. Hispanics and Hospice: A Systematic Literature Review. *Am J Hosp Palliat Care*. 2023 May;40(5):552-573. doi: 10.1177/10499091221116068. Epub 2022 Jul 18. PMID: 35848308; PMCID: PMC9845431.

End-Of-Life Considerations in the care of Latino patients

Importance of cultural humility and responsiveness:

- the Hispanic community is diverse
- we must always approach patients as individuals and use cultural humility

Hispanic patients and EOL care:

- more likely to die full code
- less likely to have discussions regarding prognosis or to have heard about hospice care than their non-Hispanic white counterparts

Cultural considerations:

- Hispanic cultures tend to value collective decision-making processes
- not uncommon for Hispanic caregivers to ask to shield the patient from being informed of their terminal diagnosis
- Families may favor providing hope and encouragement to the patient as being more important than prognostic discussions
- patients may choose to not receive a prognostic disclosure from their clinicians
- Paternalistic approaches to healthcare decision-making are common
- not uncommon for patients to prefer physician-directed decision-making

Challenges Providing EOL Care to the Latino population

Language

- Miscommunication, misunderstandings
- Lack of high-quality interpreters
- Multiple Spanish dialects
- Assess understanding by using 'teach backs' at regular intervals

Lack of cultural sensitivity training:

- Cultural humility
- Ongoing process, a commitment, self-reflection, self-critique with the goal of working effectively within the cultural context of the patient

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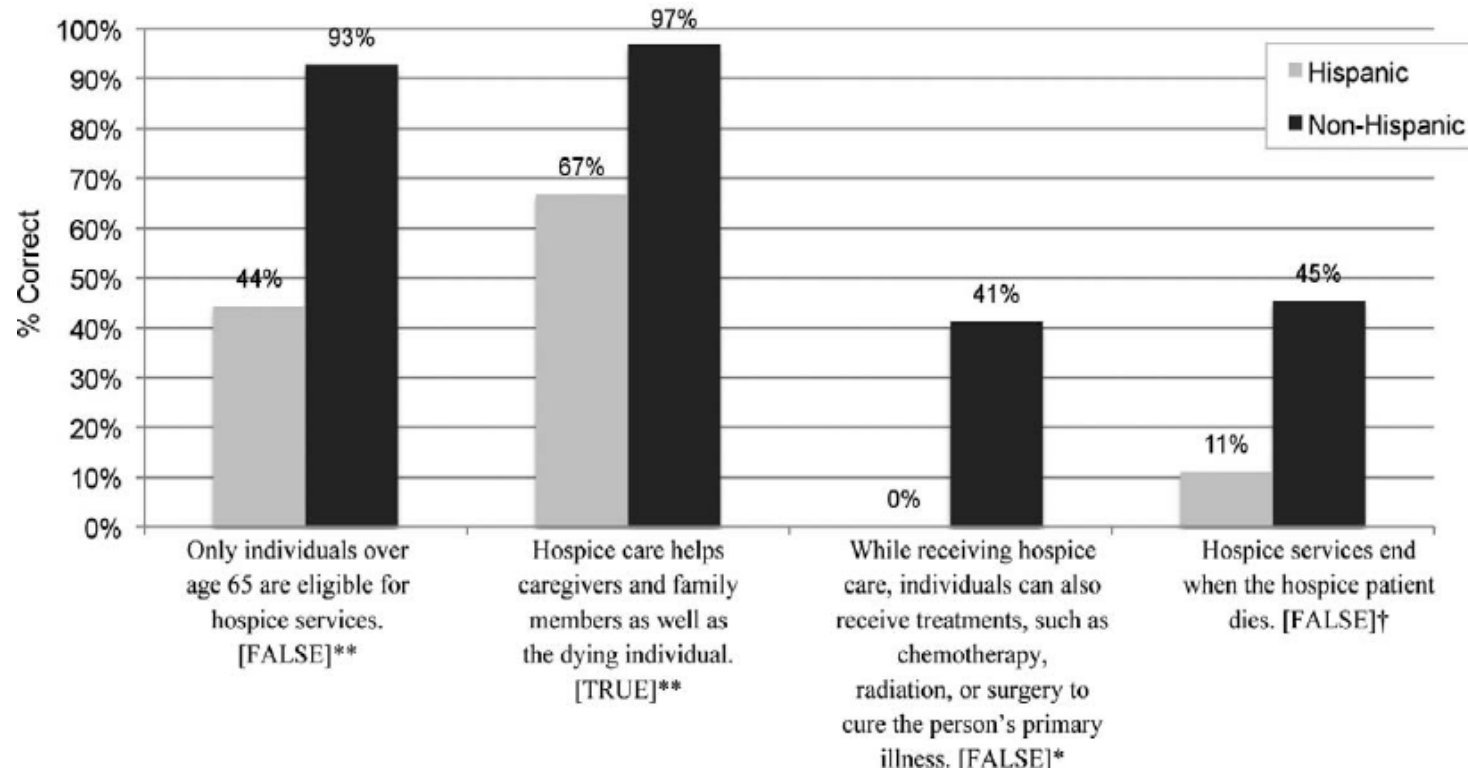
Cultural context

- Decision-making patterns tend to be family-centered “familismo”
- Advanced Care Planning may seem unnecessary
- Patriarchal family structure (gender roles)
- Respect/Obey authority (health care professionals)
- Desire to shield loved ones from being informed of a terminal diagnosis

Misconceptions and Lack of Knowledge

- Stigma of the word hospice
- “hospicio”
- Lack of knowledge about Palliative Care and Hospice

Knowledge About Hospice Care and Pain Management: Differences between Hispanics and Non-Hispanics



Carrion IV, Cagle JG, Van Dussen DJ, Culler KL, Hong S. Knowledge About Hospice Care and Beliefs About Pain Management: Exploring Differences Between Hispanics and Non-Hispanics. *Am J Hosp Palliat Care*. 2015 Sep;32(6):647-53.

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Spirituality/Religion:

- Believe that God determines the outcome
- Interfering with God, “we are believing for a miracle...”
- Death/suffering a natural part of life, delay in seeking care

Lack of Access:

- Un/under insured
- Citizenship status

Mistrust

- Perceived discrimination

Latino Pediatric Population

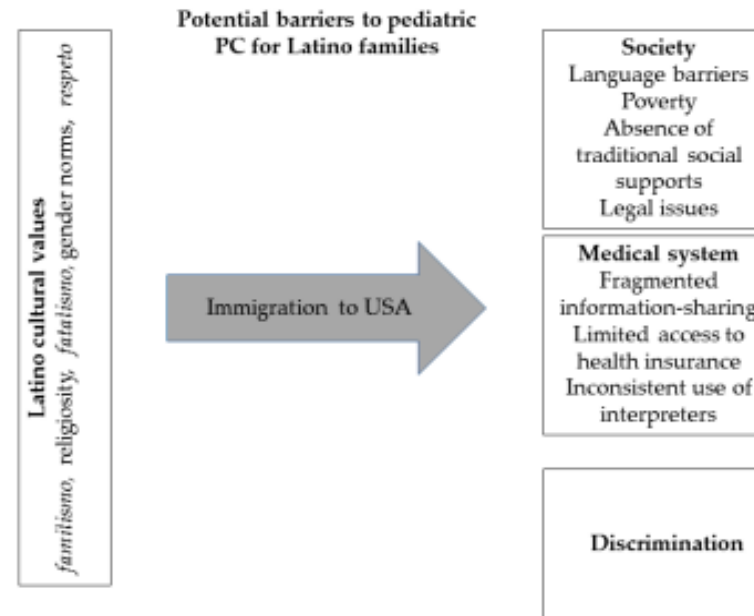


Figure 1. Mediators of the pediatric palliative care (PC) experience for latino families.

Muñoz-Blanco S, Raisanen JC, Donohue PK, Boss RD. Enhancing Pediatric Palliative Care for Latino Children and Their Families: A Review of the Literature and Recommendations for Research and Practice in the United States. *Children (Basel)*. 2017 Dec 22;5(1):2. doi: 10.3390/children5010002. PMID: 29271924; PMCID: PMC5789284.

Didactic Presentation Q&A

Case Study Presentation

“Please let me give mom the news”

Situation

- Mrs. G is a 72 y/o Hispanic female patient with past medical history of hypertension, osteoarthritis and hypothyroidism. Over the past 6 months she has been feeling more fatigued, with decreasing appetite and weight loss of 50 pounds. Over the last three weeks she has developed jaundice, abdominal pain, nausea and vomiting. She is only tolerating liquids at this point.
- Her husband, Mr. S, called their daughter N. who is a nurse and she instructed him to immediately take patient to the Emergency Department. During the Emergency Room evaluation most of the history is provided by the patient's husband since Mrs. G is of limited English proficiency and she is asleep during most of the encounter.
- A CT of her abdomen is ordered and reveals a large likely inoperable pancreatic mass. The ER physician, who only speaks English, comes back to the room, sits at the bedside and explains the findings to both patient and husband. During the encounter patient nods on and off at what the doctor says. Mr. S verbalizes understandings but doesn't ask any further questions. Instead, he quickly summons the doctor outside to continue the conversation.
- Once he is done talking to the doctor he calls his daughter, Mrs. N., who tells him "don't tell mom she has cancer. I will head that way tonight".

Background

- Mrs. G is married to Mr. S. She was a homemaker and took care of their daughter while Mr. G worked as a Taxi driver. They have only one daughter, N, who is pregnant with her first child and just started a new nursing job. She lives 6 hours away. Patient and husband have tried “not to be a burden” to their daughter with so much going on in her life at the time. Patient is of Catholic faith and her faith is very important to her. Up until two months ago she visited her church regularly. She does not have Advanced directives.
- The next morning, their daughter arrives to the hospital and when the medical team makes their rounds, she and her father are waiting for them outside of the room. She tells them that the patient doesn’t understand what is happening and tearfully asks if instead of using interpreters she can be the one to tell her mother since she has medical knowledge and “mom will take the news better from me”.
- The medical team tells her that while they appreciate and understand her desire to help and protect her mother, it is best if she focuses on being a support to her mother at this time and that it would be to the benefit of her mother and her if they use an interpreter. After some hesitation family agrees.

Assessment

- Patient is told with the assistance of a medical interpreter about her diagnosis. After discussing treatment options with the Oncology and Palliative Care teams, she decided to go home with hospice support.
- Patient eventually got a biliary stent to manage her jaundice, was started on opioids and felt much more comfortable at the time of discharge.
- The social worker at the hospital helped coordinate transition of care to a home hospice company with Catholic affiliation and discussed with their case manager expected language barriers so they could coordinate mobilizing Spanish-speaking staff if and when available to better serve the needs of Mrs. G.
- The hospice company arranged for patient to receive her Last Rites and in addition to nursing and medical staff she was visited by nuns which gave Mrs. G great comfort.
- She passed peacefully two months later at her home surrounded by her family.

Discussion and Recommendations

Discussion and Recommendations

- What could have the ER physician done differently?
- Does nodding necessarily mean understanding?
- Can/should medical information be withheld from patients to protect them?
- Should family members serve as interpreters of difficult medical news?
- What is the importance maintaining a therapeutic alliance with the patient's family?
- What are some of the potential benefits or risks associated with allowing family members be interpreters?
- What is the importance of providing patients and families with high-quality interpreters?
- Was this family approached with cultural humility?

Key Takeaways

- Latino/Hispanic population is growing and widely diverse
- Latinos are under-represented when it comes to receiving Palliative and Hospice Care
- Be mindful of common cultural patterns such as collective decision-making processes or “familismo”
- Do not assume non-native English speakers are comfortable having complex, high-stakes medical discussions in English, even if they seem proficient at English language!
- Professional interpreters are necessary and recommended to bridge the gap of inequality in accessing health care services
- Be aware that mistrust towards providers has been documented among underserved populations
- The importance of maintaining a therapeutic alliance with the patient’s family
- Advocacy efforts with a focus on equitable care and policy reform are essential to improving the health of this and other vulnerable populations

References

1. Cardenas V, Fennell G, Enguidanos S. Hispanics and Hospice: A Systematic Literature Review. *Am J Hosp Palliat Care*. 2023 May;40(5):552-573. doi: 10.1177/10499091221116068. Epub 2022 Jul 18. PMID: 35848308; PMCID: PMC9845431.
2. Seaman Giannina. "Hispanic, Latino, Latin(x), Spanish: Clarifying Terms for Hispanic Heritage Month". Ketchum, [18 September 2020](https://www.ketchum.com/hispanic-latino-latinx-spanish-clarifying-terms-for-hispanic-heritage-month/), <https://www.ketchum.com/hispanic-latino-latinx-spanish-clarifying-terms-for-hispanic-heritage-month/>
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4. Wells D, Moustafa Yara, Vazquez R Adriana. Fast Facts and Concepts #469. End-Of-Life Care Considerations for the Hispanic Patient in the United States. July 2023. Available at: <https://www.mypcnow.org>
5. Ramirez, Diana, "BARRIERS TO THE USE OF PALLIATIVE AND HOSPICE CARE AMONG THE LATINO POPULATION" (2022). Electronic Theses, Projects, and Dissertations. 1369. <https://scholarworks.lib.csusb.edu/etd/1369>
6. Carrion IV, Cagle JG, Van Dussen DJ, Culler KL, Hong S. Knowledge About Hospice Care and Beliefs About Pain Management: Exploring Differences Between Hispanics and Non-Hispanics. *Am J Hosp Palliat Care*. 2015 Sep;32(6):647-53. doi: 10.1177/1049909114536023. Epub 2014 Jun 5. PMID: 24907120.
7. Campinha-Bacote, J., (December 4, 2018) "Cultural Competemility: A Paradigm Shift in the Cultural Competence versus Cultural Humility Debate – Part I" *OJIN: The Online Journal of Issues in Nursing* Vol. 24, No. 1.

Session Evaluation and Certificate of Completion

- Your feedback is valuable as we plan upcoming sessions!
- Project ECHO sessions are not accredited for continuing education, but we are able to offer a confirmation of completion for each session. To receive confirmation of completion, please complete the following [Project ECHO Session Evaluation and Knowledge Check](#) following each session.

NHPCO Health Equity Certificate

- Would you like to demonstrate your commitment to delivering culturally competent care across the continuum of serious illness in an equitable, inclusive, and person-centered manner?
 - NHPCO is pleased to offer a Health Equity Certificate for individuals who participate in at least 17 sessions in the *Equity Where It Matters* series
- Participants interested in earning the Health Equity Certificate must complete the [Project ECHO Session Evaluation and Knowledge Check](#) following each session.
- Effective July 20, the Session Evaluation and Knowledge Check can be completed using one link for each session.
- Session Evaluation and Knowledge Check links are unique for each Project ECHO session and do not expire. Links for each 2023 session can be found on the [NHPCO Project ECHO webpage](#).

Upcoming Sessions

Date: September 28

Topic: Supporting Patients Experiencing Housing Insecurity at the End of Life

Date: October 19

Topic: Culturally Responsive Trauma Informed Care

Additional Information

NHPCO Project ECHO webpage:

<https://www.nhpc.org/regulatory-and-quality/quality/projectecho/>

NHPCO Project ECHO session recordings and Key Takeaways:

<https://www.nhpc.org/regulatory-and-quality/quality/projectecho/2023-project-echo-session-recordings/>

NHPCO Project ECHO Registration Link:

<https://nhpc.zoom.us/meeting/register/tZEsfu-trz4oGtQeKFw41UEIYNwjSli8QCBF>

For more information:

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